Links Between Autism Spectrum Disorder Diagnostic Status and Family Quality of Life

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Background

- Quality of life is often lower, relative to the general population, in families of children with a learning disability or neurodevelopmental disorder [1,2]
- This effect may be particularly pronounced when children have both a learning disability and an autism spectrum disorder [3]

also

- There is a push in policy and clinical practice for earlier diagnosis of autism spectrum disorder, with concern over waiting times in some areas [4]
- However it is unclear what impact having a diagnosis has on families' quality of life and stress

We aim to examine the interaction between child characteristics, including learning disability and features of autism, and diagnostic status and the way in which these factors, separately and in combination, influence family experiences.

Methods

The study capitalised on an existing larger cohort of young people with additional needs, originally referred by teachers from schools in Scotland. A sub-sample of mothers (n=76) of young people aged 13-22 years then took part in this exploration of quality of life factors. This sample was also completed by an additional n=17 mothers of typically-developing young people. Mothers completed the following questionnaires

- **Child Behaviour Checklist** to capture challenging behaviour levels
- **Social Communication Questionnaire** to screen for autism symptom levels
- **WHO Quality of Life** survey to evaluate maternal quality of life
- **Family Stress and Coping Interview** to evaluate maternal stress (not mothers of TD young people)
- In addition, for some families we acquired quality of life data from fathers and unaffected siblings using the **Family Quality of Life Survey**

On the basis of these scores the participants were organised into four groups:

1. Having additional needs, a negative SCQ screening score and no diagnosis of autism (n=41)
2. Having additional needs, a positive SCQ screening score and an existing diagnosis of autism (n=18)
3. Having additional needs, a positive SCQ screening score but no existing diagnosis of autism (n=17)
4. Typically-developing controls (n=17)

Table 1: Demographic data by group

		1	2	3	4
		Additional needs			Typically developing
		-ve SCQ	+ve ASD	+ve SCQ and -ve ASD	
		n=41	*n*=18	*n*=17	*n*=17
Age*	mean	15.60	16.35	16.06	15.85
	sd	1.9	2.34	1.40	1.7
Gender	no. (%) male	23 (56%)	17 (95%)	12 (71%)	8 (47%)
IQ	mean	72.78	84.06	66.50	111.82
	sd	16.86	22.08	9.35	16.88
School	Mainstream	20 (49%)	7 (39%)	3 (18%)	15 (88%)
	Special	17 (41%)	9 (50%)	11 (65%)	0
	FE College	4 (10%)	2 (11%)	3 (18%)	2 (12%)
SCQ	mean	7.53	22.89	20.06	0.59
	sd	3.87	5.83	3.38	0.79
CBCL	mean	67.00	81.44	89.65	11.24
	sd	33.43	29.29	49.27	10.85

** There were no significant differences in mean age between the 4 groups.*

Fig 1a: WHO-QoL mean scores by group

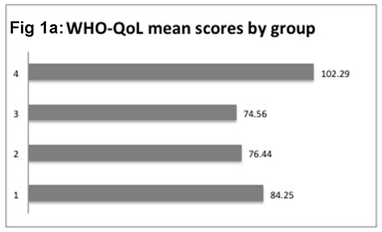

Fig 1b: FQoLs mean scores by group

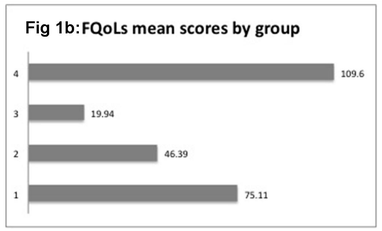

Figure 1: These graphs illustrate higher quality of life in mothers (1a) and families (1b) of young people without additional needs. The lowest quality of life scores are apparent in group 3 - young people having positive SCQ screening scores but no clinical ASD diagnosis

Table 2: Correlations between study variables

	SCQ	CBCL	WHOQoL	FQoL	FSCI	IQ
CBCL	r(76) = .385*					
WHOQoL	r(75) = -.349*	r(75) = -.406*				
FQoL	r(73) = -.378*	r(73) = -.250*	r(72) = .587*			
FSCI	r(74) = .474*	r(74) = .363*	r(74) = -.564*	r(71) = -.464*		
IQ	r(65) = -.147	r(65) = -.125	r(65) = .028	r(63) = -.071	r(64) = -.057	
Age	r(76) = .155	r(76) = -.034	r(75) = -.065	r(73) = -.204	r(74) = .157	r(65) = -.400

* significant at p<.001

Results: group differences in stress and quality of life

- WHOQoL scores differed between groups, $F_{(3,87)} = 11.91$, p<.01
  - Planned contrasts indicated scores for Group 4 > Group 1 > Groups 2 & 3 (all p<.05)
  - These findings are illustrated in Figure 1a
- FQoLs questionnaires were completed by a total of 63 additional family members across all groups in the study, including fathers, siblings and young people themselves.
  - Results again indicate a significant difference between groups, $F_{(3,83)} = 9.88$, p<.01
  - Planned contrasts indicate Group 4 > Group 1 > Groups 2 > Group 3 (all p<.05)
- FSCI scores reveal lower stress in mothers of young people in Group 1. but no significant difference between groups 2 and 3.

FSCI mean scores by group

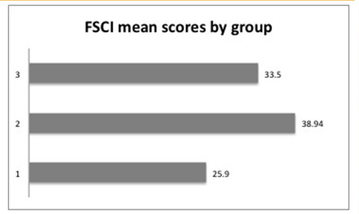

Figure 2: The lowest stress scores are found in group 1 - mothers of young people with no signs of ASD and no diagnosis.

Results: relations between measures

What can explain differences between groups on QoL measures?

- Correlations indicate that quality of life is related both to SCQ and CBCL scores, but not to IQ or age (Table 2)
- CBCL scores (see Table 1) are highest in groups reporting the lowest quality of life scores
- Levels of challenging behaviour are significantly different between groups as follows:
  Group 4 < Group 1 < Groups 2 and 3
- In addition, partial correlations reveal that SCQ scores retain significant relations to quality of life and stress when controlling for CBCL (Table 3)

Table 3: partial correlations controlling for challenging behaviour levels

Control variable		SCQ
CBCL	FQoL	-.319**
	FSCI	.369**

** significant at p<.001

What can explain the absence of a clinical diagnosis in Group 3?

- When comparing group 2 and group 3 we find:
  - No differences in SCQ score
  - No differences in CBCL score
  - No difference in access to, or perceived quality of, specialist services
  - Significantly lower IQ in the undiagnosed group
  - More females…
- It is unclear, particularly in respect to gender, which of these differences are clinically as well as statistically significant

Conclusions

- Families of children with additional needs experience stress and relatively low quality of life, more so in the presence of autism, and this is most marked when social communication problems are present, but ASD is not diagnosed
- The poorest quality of life scores cannot be fully explained by lack of access to services, intellectual or behavioural profiles or degree of social communication difficulty
- We speculate that having a low IQ score may be a factor contributing to missed diagnosis of ASD
- In addition, it seems probable that the absence of a clear diagnostic explanation for a pattern of difficulties may in itself contribute to maternal stress and impair quality of life

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